RESEARCH HIGHLIGHT

November 2008 Socio-economic Series 08-017

Adapting Your Home to Living with Dementia

A Resource Book for Living at Home and Guide to Making Home Adaptations

INTRODUCTION

Dementia impairs cognitive capacity—the ability to think, remember, understand, reason, judge and communicate. The loss of these abilities affects an individual's capacity to function and perform daily activities, such as handling finances, cooking and driving. There are several types of dementia, the most common being Alzheimer Disease.[1]

There are an estimated 364,000 Canadians over the age of 65 who have some form of dementia,[2] 50% of whom live in the community, 29% of whom live alone.[3] Each person experiencing dementia faces challenges that potentially compromise their safety and quality of life at home. A supportive environment is crucial for individuals with dementia since the disease affects not only physical capabilities but the ability to adapt behaviour to the environment.

Environmental adaptation or modification is an intervention approach used to enhance people's safety and security and maximize their ability to participate in society. It involves strategies such as modifying physical objects, simplifying task performance, introducing assistive devices or making home alterations. Although many issues for creating a supportive environment are similar to the safety and accessibility concerns of people with physical disabilities, cognitive and behavioural symptoms also need to be considered for persons with dementia, as well as the appropriate selection, introduction and timing of physical adaptations. Furthermore, the family's ability to understand how to adapt the environment is also critical, as it is often the family that provides most of the supportive care for a person living with dementia in the community.

This study was carried out by Nancy Rushford, MA, MSc (OT) with financial assistance under the External Research Program of Canada Mortgage and Housing Corporation (CMHC). It involved close collaboration with the Alzheimer Society of the Niagara Region[4] (ASNR) in Ontario and a group of extraordinary individuals living with dementia and their caregivers.

OBJECTIVES AND RESEARCH QUESTIONS

The objective of this study was to develop an educational resource on environmental adaptation for people with dementia living at home and their caregivers.

The study was inspired by families who sought support from ASNR to deal with the many challenges associated with dementia. Individually, these families had unique stories to tell. Collectively, they had a common experience and a wealth of knowledge and expertise that they had developed while coping with the disease. It was anticipated that a useful and practical educational resource—that could guide other individuals with dementia and their caregivers—could best be created by combining the knowledge and expertise of these families, the expertise of family support counselors at ASNR and information available in the existing literature. The involvement and input of individuals with dementia and their caregivers was fundamental to the research process.

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1 *Housing Options for People with Dementia*, 1999, Canada Mortgage and Housing Corporation.

2 Alzheimer Society Canada, 2007.

3 Alzheimer Society Canada. Canadian Study of Health and Aging Working Group: Patterns of caring for people with dementia in Canada. *Can J Aging* 1994; Vol. 13 no. 4: 470-487. English and French. Retrieved August 2008 from http://www.alzheimer.ca/english/disease/stats-caregiving.htm.

4 The Alzheimer Society is a non-profit agency operating nationally, provincially and locally in Canada. The Alzheimer Society of the Niagara Region serves as a source of education, support, and advocacy for persons with dementia, their family members, health providers and the general public.

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There were three primary research questions for the study.

1. What are the experiences of individuals with dementia living at home and family caregivers providing home based care for them?
2. What specific difficulties do they experience in the home and community and how do they cope with these difficulties?
3. What steps and strategies—from the environmental adaptation viewpoint—can be taken to alleviate these difficulties?

METHODOLOGY

A practical action research approach was used to conduct the study, including focus groups and semi-structured interviews with seven family caregivers and seven persons in the early stage of dementia. It involved an exploration of the lived experience of dementia and caregiving, including difficulties and functional implications, as well as coping strategies. These study participants were engaged in the process of incorporating their knowledge and experiences, issues and coping strategies into the resource on environmental adaptation and informing its development until completion.

Study participants were selected by purposive sampling and recruited through the ASNR. Informed consent was obtained from all participants.

The research was conducted at the ASNR and in the study participants' homes, which were also located in the Niagara Region.

The study was conducted in seven phases.

Phase One – initial focus groups and first draft of the educational resource

Phase One consisted of two focus groups—one with caregivers; the other with people with dementia. The objective was to explore the lived experiences from the perspectives of family caregivers and individuals diagnosed with dementia. A semi-structured questionnaire was developed, pilot-tested and finalized for each group; and a facilitator with extensive experience in dementia and psycho-social support used it as a guide to conduct the focus groups. Each focus group was audiotaped and transcribed, and a research assistant recorded field notes and observations. The primary investigator analyzed the data and produced the first draft of the educational resource *Adapting Your Home to Living with Dementia.* This first draft identified difficulties commonly experienced by persons with dementia and their families at various stages of dementia and categorized them by themes and types of activities carried out in the home and community.

Phase Two—second focus groups and input from staff members of the ASNR

Two additional focus groups—one with caregivers; the other with people with dementia—were conducted with the same people who participated in the first focus groups. The objective was to verify emerging themes and elaborate on the list of difficulties with everyday activities and coping strategies that had been identified in the first focus groups. The second focus groups were also audiotaped and transcribed and a research assistant collected field notes.

The procedure for collecting data differed slightly for each group. The caregiver group was introduced to the first draft of the educational resource together as a group and participants were asked to reflect further on their experiences as a group.

In contrast, the persons with dementia group was not only asked to verify and elaborate on emerging themes as a group, but also individual participants were introduced to the first draft of the educational resource through one-on-one interviews in their homes. The interviewer recorded their responses to the draft in writing. Collecting data through one-on-one interviews in the home provided a more comfortable and appropriate environment where individuals with dementia could concentrate and more easily express themselves. It also provided a meaningful context to elicit responses to questions related to their activities around the home.

Furthermore, seven staff members of the ASNR, including family support counsellors, the clinical services director and the educational specialist, were given a copy of the first draft of the educational resource. They were asked to elaborate on the issues presented in terms of difficulties experienced with activities around the home and community as it related to their experience with people with dementia and their caregivers. They identified common difficulties they had observed that were not represented in the draft and added their suggestions and recommendations for adaptive strategies/home modifications.

Phase Three—second draft of the educational resource

In Phase Three, the principal investigator analyzed the data from the focus groups and interviews conducted in Phase Two. She then carried out a literature review on environmental adaptations for dementia and the experience of dementia from the perspective of caregivers and individuals living with the disease and compiled emerging common themes, issues, challenges and coping strategies with relevant literature on the topic and the input from the ASNR staff. Using this information, she prepared the second draft of the educational resource.

Phase Four—feedback on second draft of the educational resource

In Phase Four, a form was developed to obtain feedback from study participants on the content, relevance, style and layout of the second draft of the educational resource. A copy of this form and the draft of the educational resource were distributed to all participants, including ASNR. A week later the research assistant met with each study participant (persons with dementia and their caregivers) in their homes to discuss the draft and complete the form. ASNR staff completed the form independently.

Phase Five—pilot test of the third draft of the educational resource

In Phase Five, the principal investigator reviewed feedback received on the second draft of the educational resource and revised the resource accordingly. The resulting third draft of the educational resource was then pilot-tested with people who were not familiar with it. These included three ASNR family support counsellors, three caregivers and three persons with dementia. The research assistant met with participants in the pilot phase on a one-on-one basis in their homes. They were introduced to the resource and given a copy of it to review along with a feedback form to complete. Two weeks later the research assistant returned to obtain feedback. Where assistance was needed the research assistant helped the participant complete the form.

Phase Six—pilot test of the fourth draft of the educational resource

The fourth draft of the educational resource was further pilot-tested with one caregiver and one ASNR family support counsellor who had never seen the educational resource before. Further revisions were made to the resource to reflect their feedback.

Phase Seven—final version of the educational resource

In Phase Seven, the final version of the educational resource *Adapting Your Home to Living with Dementia: A Resource Book for Living at Home and Guide to Making Home Adaptations* was completed.

FINDINGS

This study revealed that living with dementia involves a process of adaptation experienced as a dynamic tension between the person with dementia and his or her caregiver, typically a spouse or an adult child. This tension manifested as "holding on vs. letting go" (caregivers) and "autonomy vs. self doubt" (persons with dementia). Caregivers were primarily concerned with safety and security, and particularly with how to minimize risks and protect their loved ones from experiencing failure. People with dementia expressed concerns about wanting to maintain their independence yet needing and being grateful for help. Empathy, gratitude and humour were the primary coping mechanisms by which both groups managed this tension.

CONCLUSIONS

Dementia places major demands on individuals living with the disease and their family members providing care for them. Understanding the caregiving relationship and particularly how people with dementia and family caregivers naturally attempt to adjust and cope is an important starting point in interventions involving environmental adaptation. Adapting the home to living with dementia involves more than simply making physical changes to the home, introducing assistive devices, simplifying tasks or adapting one's approach. It is a process that occurs within the context of relationships. In fact, research shows that adherence to recommendations for environmental adaptation is a complex process including factors such as purpose and meaning attributed to aspects of the home environment, caregiver skills and ownership of ideas, personal resources, and formal and informal supports. Consequently, health care professionals need to promote a collaborative approach to environmental adaptation that fosters joint decision-making, provides clients with information, options and choices and ensures that both the caregiver's and care receiver's needs and preferences are respected. Providing families with a variety of options to suit their individual circumstances and strategies to overcome resistance to intervention are key factors to enhancing their capacity to adapt their homes to living with dementia.

The report that resulted from this research, *Adapting your Home to Living with Dementia* integrates the findings from the research into practice in that it incorporates a guide to home adaptation into the bigger picture of the experience of dementia and the care-giving relationship.

Incorporating the knowledge and experiences of people living with dementia and family caregivers into a practical and easily accessible educational resource will potentially serve the following key functions:

1. Bridge the gap between research and practice;
2. Empower families to access and use formal supports according to their needs; and
3. Support and encourage individuals and families to strengthen their skills and strategies used to cope with dementia.

Adapting Your Home to Living with Dementia is organized in two volumes. Volume One contains the research report; Volume Two the "Resource Book" and "Guide to Home Adaptations."

The "Resource Book" provides general information about dementia, its symptoms and common problems that impact every day activities of people with dementia and their caregivers. It also contains strategies that can help people with dementia to continue to live safely in their home for as long as possible. In the book, individuals with dementia and their caregivers share their thoughts, feelings and experiences about living and coping with dementia.

The "Guide to Home Adaptations" provides suggestions and strategies to deal with difficulties associated with dementia and caregiving at home. These suggestions and strategies address cognitive and physical issues and are designed to make it easier for people with dementia to perform daily living activities in the home and the community. The guide is organized in the following three sections.

A. "General Household Activities"

B. "Activities of Daily Living"

C. "General Community Activities"

Each of these sections is further organized into topics that reflect the types of difficulties that people with dementia and their caregivers typically experience. Tips and strategies to help manage these difficulties are also provided and, at the end of each section, there is a "Self Assessment Form" and a "To Do List" designed to help users make a list of, and prioritize, the most appropriate home adaptations.

Adapting Your Home to Living with Dementia is intended primarily for people with dementia living at home and their caregivers, but it can also be useful to community-based health professionals and local Alzheimer Societies as a tool to help individuals with dementia and their families. *Adapting Your Home to Living with Dementia* has been designed to complement other available resources.

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Research Report: *Adapting Your Home to Living with Dementia: A Resource Book for Living at Home and Guide to Making Home Adaptations*

Principal Investigator: Nancy Rushford M.A., MSc. (Occupational Therapist)

Research Team Members: Staff at the Alzheimer Society of the Niagara Region (ASNR) and a group of extraordinary individuals with dementia and their caregivers living in the Niagara Region.

This project was funded (or partially funded) by Canada Mortgage and Housing Corporation (CMHC) under the terms of the External Research Program (ERP), an annual research grant competition. The views expressed are the personal views of the author(s) and do not represent the official views of CMHC. For more information on the ERP, please visit the CMHC website at **www.cmhc.ca** or contact the Project Officer, Responsive Programs by e-mail at erp@cmhc-schl.gc.ca, or by regular mail: Project Officer, Responsive Programs, External Research Program, Policy and Research Division, Canada Mortgage and Housing Corporation, 700 Montreal Road, Ottawa ON K1A 0P7.

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Printed in Canada
Produced by CMHC 08-10-08

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